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Research Article

The creation of meaning – Intensive care nurses' experiences of conducting nurse-led follow-up on intensive care units

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ABSTRACT

Objective: To explore and describe the experiences of Norwegian intensive care unit nurses providing nurse-led follow-up to patients and their families.
Design and methods: The study had a qualitative design with a phenomenological approach. Three focus-group interviews were conducted with nurses on three intensive care units. Giorgi's phenomenological method guided the analysis.
Findings: The creation of meaning emerged as a general structure describing intensive care nurses' experiences of nurse-led follow-up. When caring for critically ill patients, nurses described becoming emotionally moved, which motivated them to perform nurse-led follow-up procedures, such as writing in patient diaries. A general wish to give context to the patients' time spent in intensive care emerged. When conducting nurse-led follow-up, the nurses made personal contributions, which could be emotionally challenging for them. Overall, nurse-led follow-up was found to increase nurses' insight into and motivation for their own practice.
Conclusion: The performance of nurse-led follow-up appears to be grounded in care for and engagement in individual patients and families. The nurses studied wanted to help patients and families to be able to handle their experiences during an intensive care stay. In addition, nurse-led follow-up gave meaning to the intensive care nurses' own practice.

Implications for clinical practice

Performing nurse-led follow-up with intensive care patients and their families provides intensive care nurses with:

- Increased understanding of patients' experiences during their critical illnesses.
- Feedback on their own nursing practice within the Intensive Care Unit.
- Motivation to continue working with critically ill patients.
- A holistic way of understanding the needs of patients and their families, beyond the critical illness itself.

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Introduction

Although survival rates for critically ill patients admitted to intensive care units (ICUs) are rising, patients report various psychological, physical and cognitive problems after intensive care, such as anxiety, depression, post-traumatic stress disorder (PTSD), physical weakness and impaired memory (Karnatovskaia et al., 2015; Svenningsen et al., 2015). The terms *post-intensive care syndrome* (PICS) and *post-intensive care syndrome–family* (PICS-F) describe problems that may arise after critical illnesses (Elliott et al., 2014; Needham et al., 2012). To meet the challenges that occur here, various follow-up activities, often bottom-up initiatives led by intensive care nurses, have been developed and implemented over the past three decades (Jonasdottir et al., 2016; Svenningsen et al., 2015; Van Der Schaaf et al., 2015). The organisation and content of follow-up programmes differs both between and within countries (Egerod et al., 2013; Griffiths et al., 2006; Van Der Schaaf et al., 2015). Such follow-up programmes can consist of giving patients diaries documenting their ICU stays, organising appointments at ICU follow-up clinics and visits to the ICU and holding phone conversations at any time from the period immediately following ICU discharge up to 12 months later (Jonasdottir et al., 2016; Svenningsen et al., 2015). In the United Kingdon (UK), the National Institute for Health and Care Excellence providess guidelines for rehabilitation after critical illness, which include recommendations for assessments and rehabilitation measures that start during the ICU stay (NICE, 2009).

Determining the effects of nurse-led follow-up on PICS symptoms has been a research focus over the past two decades. Several studies have shown that measures such as providing diaries and implementing follow-up programmes have positive effects on patients' and families' PICS symptoms (Backman et al., 2010; Garrouste-Orgeas et al., 2012; Jones et al., 2010; Knowles & Tarrier, 2009; McPeake et al., 2017). However, other studies have reported that the use of diaries and follow-up clinics has no significant effects on patients and their families (Cuthbertson et al., 2009; Jensen et al., 2016; Jonasdottir et al., 2018; Ullman et al., 2015). Nevertheless, patients often appreciate and value these diaries and follow-up offers (Engstrom et al., 2008, 2015; Ewens et al., 2014; Glimelius Petersson et al., 2015).

ICU nurses have reported that writing diaries for intensive care patients is a means of caring for such patients (Gjengedal et al., 2010). This type of activity has also been found to strengthen nurses' relationships with patients (Ednell et al., 2017). However, writing diaries can be a challenge for ICU nurses as it can cause unwanted, strong emotional involvement with patients and families to arise (Perier et al., 2013). Engstrom and Soderberg (2010) have found that ICU nurses value meeting former ICU patients because it increases the nurses' knowledge of patients' and families' experiences during and after an ICU stay.

National recommendations for the use of diaries within ICUs were published in Norway in 2011 and form the basis of ICU nurse-led follow-up (Storli et al., 2011). The recommendations advocate that ICU nurses write diaries for ICU patients. The diaries should contain daily notes on patients' activities and events that occur throughout the ICU stay. The nurses are required to arrange delivery of the diaries to patients after ICU discharge, either at a discharge meeting or by post. A follow-up consultation should then be conducted by an ICU nurse who knew the patient during the ICU stay, once the patient has had an opportunity to read the diary. Patients may bring a family member to such consultations, if desired.

A recent survey showed that 27 of 39 responding Norwegian ICUs offered nurse-led follow-up for ICU patients (Moi et al., 2018). For 61.5% of these units, diaries were an important component of follow-up. On 17 of the units, there was either a defined ICU nurse position for nurse-led follow-up or an ICU nurse-led follow-up resource group. Additionally, it was reported that ICU nurses in charge of patients often write in patients' diaries and conduct follow-up consultations, usually within the first three months and up to six months after discharge (Moi et al., 2018). Based on these findings, it can be suggested that deeper insight into ICU nurses' experiences of nurse-led follow-up and their experiences of patients' (and, indeed, their families') follow-up needs may facilitate further development of Norwegian ICU nurse-led follow-up programmes.

Methods

Objective

The aim of this study was to explore and describe the experiences of Norwegian ICU nurses providing nurse-led follow-up. The study was guided by two research questions, which were: How do ICU nurses experience performing nurse-led follow-up? and How do the ICU nurses experience ICU patients' and their families' need for follow-up?

Design

The study had a qualitative design, with a phenomenological approach. The aim of phenomenology is to seek and describe the meanings of experiences. Such research explores not what an object is in itself but, rather, the experience of receiving an object through one's consciousness (Giorgi, 1997). When undertaking scientific phenomenology, a change from a natural attitude to a phenomenological attitude is desirable (Giorgi, 2009). Such a shift means being open to the studied phenomenon, while still being based (in the case of the present study) within a nursing perspective.

Setting and participants

A purposeful sample of nurses from three ICUs at two university hospitals and one local hospital in Norway was invited to participate in the study. The ICUs in question used nurse-led follow-up and the participating nurses were engaged in programmes such as writing diaries for ICU patients and performing follow-up consultations after ICU discharge. The first author informed a contact person at each ICU about the study and the contact person then forwarded oral and written information to eligible participants who met the inclusion criteria. The participants had to be certified intensive care nurses and the aim was to interview nurses with varying lengths of experience as intensive care nurses and ICU employment. Moreover, a group of nurses with a variety of roles in nurse-led follow-up was preferred (for instance, ICU nurses with special responsibility for nurse-led follow-up and ICU nurses who write diaries when caring for ICU patients). The exclusion criterion was having worked in ICU management during the past three years. In total, twenty intensive care nurses participated in the study, with six to eight in each focus-group interview (Table 1).

Table 1
Participant characteristics.

Focus group	Interview A (n = 8)	Interview B (n = 6)	Interview C (n = 6)
Age – mean (min–max)	51 (37–64)	55 (52–60)	48 (33–61)
Gender – female/male	7/1	6/0	6/0
Years of experience as ICU nurse – mean (min–max)	16 (4–27)	25 (19–37)	16 (7–34)
Years of working in the ICU – mean (min–max)	16 (5–21)	22 (2–30)	13 (4–25)

Ethical considerations

An invitation letter informed participants about the study's purpose and the procedure for the interviews. The ability to withdraw from the study at any time before publication of the results was emphasised. All the participants gave written consent to participate. At the focus-group interviews, the information in the invitation letter was reiterated. The participants were asked to maintain confidentiality within the focus group. Permission to store personal data and a recommendation to conduct the study were given by the Norwegian Centre for Research Data (ref. no. 48811). Permission to perform the study was obtained from the management at each ICU and notification was provided to the data protection officer at each hospital.

Data collection

Focus-group interviews were conducted at each participating ICU (n = 3) between November 2016 and January 2017. The first author (SIF) moderated the interviews, while co-author (SE) co-moderated two interviews and co-author (ALM) co-moderated one interview. Focus-group interviews are suitable for exploring a group's knowledge and thoughts on a subject, as using group interactions can generate rich information and discussion (Doody et al., 2013). Focus-group interviews using a phenomenological methodology were seen as relevant for the study of nurse-led follow-up because individual participants' stories and experiences could be gathered, and variations in the experiences expressed during group discussions could be described (Bradbury-Jones et al., 2009).

In the interview guide used to structure the focus-group interviews, the first question was: 'Will you tell me how you conduct follow-up of patients and their families at your ICU?' The interviews then covered three main areas: 1) the nurses' experiences of conducting nurse-led follow-up, 2) the nurses' experiences of patients' and their families' follow-up needs and 3) the nurses' thoughts on patient participation in follow-up. The participants were encouraged to discuss the issues with one another, while the moderator steered the interviews to ensure that all the above areas were covered. The interviews lasted an average of 90 minutes each, and were digitally recorded and transcribed verbatim by the first author.

Data analysis

Giorgi's (2009) phenomenological method, including his four analytical steps, guided the analysis. The aim of this method is to determine the structure of experiences outlined by study participants. In this case, the three focus-group interviews were first treated as individual units and analysed separately, before being merged to reveal the general structure. First, each interview transcript was read repeatedly, often while the recording played simultaneously, to give the researcher a sense of the whole interview, including the atmosphere and level of engagement in group discussion. Second, each interview transcript was read with special attention being paid to changes in meaning. Each time a change in meaning occurred, a note was made in order to enable division of the text into meaning units (Giorgi, 2012). Third, the meaning units were condensed and transformed into expressions more closely related to the nurses' perspectives on what was being said. The analysis continued with the use of NVivo version 11 to identify and gather together similar meaning units. When this process had been completed for all three focus groups, similar meanings were identified across all three interviews, producing the general structure of the interviews. The objective was to perform an eidetic reduction with an orientation towards a nursing perspective and an emphasis on the invariant meaning describing the nursing perspective on the participants' experiences (Giorgi, 2005).

In a phenomenological approach, bracketing of past knowledge is important (Giorgi, 2009). In this case, the first author was an intensive care nurse, so the author's earlier experiences and preconceptions were written down at the beginning of the study. To increase the trustworthiness of the findings, attention was given to being open to what appears, while being conscious of and sensitive to the nursing perspective. The first author led the analysis, in continuous discussion with the co-authors.

Findings

The creation of meaning appeared as a general structure for ICU nurses' experiences of nurse-led follow-up. This creation of meaning was found to involve four main areas: 1) becoming emotionally moved, 2) giving context to patients' lost time, 3) risking oneself and 4) increasing insight and motivation. The four areas cover both how nurse-led follow-up gives meaning to ICU nurses and how nurses want to create meaning for their ICU patients. Nurse-led follow-up was repeatedly described by the participants as starting at the onset of patients' critical illnesses and admittance to ICU, when the nurses start writing in the patients' diaries.

Becoming emotionally moved

The nurses highlighted the importance of caring for the same patients for long periods during an ICU stay. Continuity of care allows the nurses to become acquainted and to develop interpersonal relationships with the patients and their families, which leads the nurses to become emotionally moved. Continuity of care was found to be important when performing nurse-led follow-up. A patient becomes more than just a patient; their lives affect the nurses. The nurses described how this motivates them to perform nurse-led follow-up, potentially leading to differences in their approaches to individual patients:

> *"I am speaking for myself now, but I have to say, it is a pleasure writing [in the diary] for some patients, but others. . .excuse me, but I drop the whole thing. If I only have one shift or. . .I don't know. For some, I feel I have more to give, more contact with the family. I don't know why, but for some patients, I am more interested in writing and taking pictures than for others, I must admit"* (3c).

Descriptions appeared of how some patients emotionally move ICU nurses, which leads the nurses to think about the patients after ICU discharge: '*There are some patients you think about a lot; at least, I do. Some patients,* [I] *think about a lot*' (4c). Some described how they have tried to find out how certain patients were progressing, either through nurse-led follow-up or by asking a doctor. Some ICU nurses reported that it was meaningful and important to visit patients on the general ward. Such visits were described as both meaningful for the ICU nurses themselves and also valuable for the patients, in the nurses' experience.

Giving context to patients' lost time

The discussion revealed that the ICU nurses think it is important to give context to the time patients 'lose' during an ICU stay, a period for which a patient might have fragmented memories or even no memories at all. Providing context for patients' time includes beginning nurse-led follow-up during patients' intensive care stays by writing in patient diaries about patients' days at the ICU. The nurses explained that they see it as important to help patients make sense of their time at an ICU.

Writing diaries for patients was a topic discussed eagerly by the ICU nurses. In general, they conveyed that they thought these diaries were extremely important for patients. Several of the ICU nurses had experienced patients contacting them and being keen to receive their diaries immediately after discharge from the ICU: '*It is about letting the patients become part of their own history because they are only told by others. But by reading about it in the diary, they feel they get another insight into it*' (1a). However, cases of patients who dreaded opening their diaries had also been reported to the ICU nurses, and some nurses had experienced patients finding it challenging to read their diaries.

The ICU nurses described experiencing that the diaries meant a lot to patients, a scenario which led the nurses to make extra efforts when writing the diaries. Creating diaries that are meaningful to individual patients requires getting to know the people behind the 'patient' label, the nurses stated. A variety of ways in which to personalise patients' diaries emerged, such as describing everyday events that had happened during patients' time at the ICU or including pictures of the patients. Some nurses even enclosed other documents, such as a printed summary of a football game played by the patient's favourite team. Encouraging patients' families to write their own diaries or to write notes in the same diaries as the nurses was seen by the ICU nurses as another way of adding context to patients' time at the ICU:

> "*It means a lot to them [pictures and text written in patients'diaries by their families]. Not long ago, I had a young man whose little children had made drawings for him, which were in the diary. He remembered the drawings but was missing two of them. I turned the whole ICU upside down trying to find them, but I never did. However, it meant a lot to the patient*" (6c).

> "*It is probably those notes that mean the most to them*" (5c).

In addition, the nurses reported experiencing that showing the patients an intensive care room when they returned for follow-up visits (letting patients see a room and absorb its atmosphere and listen to the sounds made by medical equipment) could add meaning to their time at the ICU. According to one nurse, during such a visit, a patient suddenly realised that the sounds and movements of the ICU bed could explain his memories of being on a boat during his ICU stay.

Risking oneself

When the ICU nurses described being devoted to creating meaning for patients' periods of critical illness, they indicated that they became personally involved and had to show more of their individuality than usual, which could be challenging for them. The nurses described feeling upset and uncomfortable when they failed to recognise patients who returned to the ICU after discharge, especially given their experiences of how meaningful it can be for patients to meet their ICU nurses again. Performing nurse-led follow-up practices like writing in patients' diaries could be problematic, as ICU nurses have to contend with organisational factors, such as finding the time and motivation to write during busy shifts. The shape and content of the diaries also troubled some of the nurses, as the diary notes were meant to be written in everyday language, a style far from the usual language used in other documentation: '*I feel that the language is difficult, too. It is sort of unpleasant language because it borders on kind of a childish way of writing*' (1b). They described how having to tap into their own personalities and creative abilities more when writing the notes could cause unease: '*There is something uncertain about it. Can I write like this, or maybe not? It is like she said: you write in a different way, and you are afraid of disclosing the patient*' (3c).

Such diaries are seen as belonging to the patients themselves. The nurses described how they had to protect the diaries from others until the patients were able to decide with whom to share them. When patients die, the nurses handle the diaries in different ways. For some, it was natural to offer them to the bereaved families, while other nurses were more reticent, expressing concern about where the diaries could end up. Considering experiences of diary notes, including nurses' names, being published on different media platforms, some of the nurses felt uncomfortable signing their full names because they wanted to protect themselves: '*I'm thinking, we have signed with our full names, but I'm wondering if there is any way of changing that to get some protection because it is not that important who wrote what. The important thing is the content of the note*' (1b).

Increasing insight and motivation

The ICU nurses described that they gain knowledge about their own practice and increase their understanding of the life-worlds of patients and their families through nurse-led follow-up. The nurses place high value on hearing about patients' and their families' experiences of being in intensive care:

> "*It is actually extremely educational afterwards. I remember I had a patient. He was so annoying because he seemed awake, but he spat and spat all the time. I tried not to show it, but I was so irritated! Then, when I visited him on the general ward afterward, he could tell me that he had felt like he had swallowed sand, just like he was in the desert, and he was trying to spit out the sand*" (2b).

Getting feedback on one's practice offers enlightening insights, such as how nurses awaken patients at night while typing on the computer. ICU nurses described how gaining knowledge about how patients experienced their work could lead them to change their practice, doing things in a different way. In addition, meeting former patients gives meaning to the ICU nurses' practice, highlighted by experiences of joy and inspiration, which increase their motivation to continue to work with critically ill people:

> "*In some ways, it is fulfilling for us, as well, when it initially looks terrible [for the patient], and we think that it is not possible for them to recover. Then, against all odds, they recover and move on, and return walking and smiling to the ICU, together with their families; and we communicate on a completely different level.* [Laughing] *It gives us something as intensive care nurses*" (3a).

Despite the differing trajectories of individual nurse-led follow-up cases, the nurses conveyed overall that such work provides important learning that benefits patients and their families and also the nurses themselves. For example, one nurse shared a statement that a patient made during a follow-up conversation: '*Now, I* [the patient] *have a complete picture of what happened. I have my diary; I have spoken to you* [the nurses]. *Now, it is sort of behind me, so I can move on*' (6a).

Discussion

The general structure revealed by ICU nurses' experiences of nurse-led follow-up is that of the creation of meaning. Just as ICU nurses strive to create meaning for the time patients spend at the ICU, nurse-led follow-up creates meaning for ICU nurses, too. The ICU nurses interviewed here highlighted that nurse-led follow-up starts from the onset of a patient's critical illness and admittance to the ICU, which is when the nurses begin writing in a patient's diary. In addition to writing patient diaries, other important elements of nurse-led follow-up discussed by the nurses

included visiting patients on the general ward after ICU discharge and inviting patients (often along with a family member) back to the ICU for a follow-up conversation.

The nurses' wish to create meaning for patients appears to be grounded in care. According to Benner et al. (2009, p. 280), care involves the nurses' desire to alleviate vulnerability and to promote growth and health. In the present study, it was found that ICU nurses want to provide patients with possibilities to comprehend their situations during their critical illnesses, a process which is thought by the nurses to help patients handle life after intensive care.

The ICU nurses interviewed stated that nurse-led follow-up is affected by the extent to which they become emotionally moved by and develop interpersonal relationships with patients and their families. Scholtz et al., (2016) suggest that critical care nurses are attracted to the totality of patient care within ICU settings, arguing that nurses take on full responsibility for the person who is critically ill. Some critical care nurses have also described experiencing deep relationships with patients, leading to feelings of love, awe and compassion (Vouzavali et al., 2011). Other studies have highlighted how the nurse-patient relationship within critical care is affected by the experience of closeness to and affinity with some patients, which may lead to the development of a caring relationship (Beeby, 2000; O'Connell, 2008). Our study results are in line with these findings. Some patients made strong impressions on the nurses, which strengthened the desire to perform nurse-led follow-up activities, such as diary writing and visiting the patients on the general ward. Through these activities, the nurses gained more insight into the patients' situations and developed increased motivation to continue their work, both in terms of nurse-led follow-up and general work in the ICU setting. This finding is in contrast, however, with a study by Ednell et al. (2017), in which the action/reaction order was converse. Their results indicate that diary writing leads nurses to experience deeper relationships with patients.

On the other hand, in line with our findings, several studies suggest that caring relationships that move nurses emotionally can also cause strain, from which they may feel the need to protect themselves (Beeby, 2000; Perier et al., 2013). The variations in nurse-patient relationships are considered by Segaric and Hall (2015), who have developed a theory of progressive engagement. The theory contain three stages, each of which involves a different level of engagement, from just doing one's job, to doing one's job with solicitude and doing one's job with heart. The theory indicates that interpersonal dynamics influence how nurses, patients and the families of patients construct relationships (Segaric & Hall, 2015). This theory might explain the variations in our study participants' feelings of responsibility, resulting in the ICU nurses performing more nurse-led follow-up for some patients than for others. The ICU nurses interviewed highlighted that becoming emotionally moved and experiencing interpersonal relationships with patients and/or their families motivated them to conduct nurse-led follow-up. One might also ask whether nurse-led follow-up for patients and their families after intensive care should be the responsibility of all the nurses working at an ICU or whether it should be allocated to certain nurses with special training (in, for example, conducting conversations with persons suffering from PICS syndromes such as anxiety and PTSD) or to other health care personnel altogether. A recent review revealed that there is a lack of research on which organisation of follow-up programmes after intensive care is the most effective (Schofield-Robinson et al., 2018).

The ICU nurses participating in the present study seemed to emphasise the importance of providing context for the time patients spend in ICU. Such context involves considering a patient's whole being during the intensive care stay, from factual content and information about what has happened each day to more situational aspects, including meeting the ICU nurses who cared for them, seeing an intensive care room and listening to the sounds made by the ICU equipment. The nurses described how they try to create diaries that will help individual patients in their ongoing lives after their critical illnesses. Through discussions about these diaries, both a caring dimension and a therapeutic dimension come to the fore, a finding which is in line with earlier research (Ednell et al., 2017; Egerod & Christensen, 2009; Egerod et al., 2011; Gjengedal et al., 2010). The nurses explained how they strive to get to know each individual patient, drawing on their own personalities and creativity in doing so in order to produce diaries that may be useful for patients after an ICU stay. While the ICU nurses in this study appeared convinced about the positive effects of providing context for the patients' 'lost' time during an ICU stay, they also spoke of experiences where patients had found it challenging to look at their diaries. The question of whether or not the provision of diaries and nurse-led follow-up is always positive has been discussed internationally in existing literature, and more research is needed to provide more detail on patient experiences of receiving nurse-led follow-up care, including diaries (Aitken et al., 2017a, b).

The ICU nurses studied here also described putting themselves at risk, to some extent, when striving to create meaning for patients' time in an ICU setting. Benner and Wrubel (1989) highlight that the process of making something matter is a precondition for caring. By caring, the nurses open themselves up to the persons they meet. They become close at a time when the patients and their families are vulnerable and might experience crisis. Some participants felt challenged and described feelings of unease, especially regarding the use of diaries. Ednell et al. (2017) describe how complicated the diary is, despite its simplicity: it is a low-tech aid, but writing the 'right' thing might be a complex task. It seems that the process of aiming to make the diary personal to the patient also makes the diary personal to the nurse in question. In an analysis of ICU survivors' diaries, Egerod and Christensen (2009) find that such diaries also disclose nurses' own performance levels. The nurses become personally involved and invested in the patients' diaries, and this investment might explain why some of the ICU nurses examined here expressed concern about handling the documents – for example, about whether or not to give diaries to bereaved families. It can be concluded, then, that in becoming emotionally involved and conducting nurse-led follow-up, the nurses may become vulnerable themselves (Angel & Vatne, 2017; Carel, 2009; Gjengedal et al., 2013).

Limitations

This study has reported on the experiences of ICU nurses and is limited, therefore, by its failure to involve ICU patients and their families. It should be noted, however, that the present study is part of a larger project, which also examines the experiences of ICU patients and their family members. The present study consisted of three focus-group interviews held at three Norwegian ICUs. All the participants in each group knew one another. Although consideration was given to providing a safe environment in which the participants could freely express their opinions, some of the participants may not have felt comfortable with expressing themselves fully in front of colleagues. This may have led to some group conformity.

Conclusion

The performance of nurse-led follow-up appears to be grounded in care. When caring for individual patients and their families, ICU

nurses undertake nurse-led follow-up practices, including writing in patients' diaries, visiting patients on the general ward, and offering patients and their families follow-up conversations and visits to the ICU after hospital discharge. The results show that conducting nurse-led follow-up creates meaning for ICU nurses, providing them with knowledge, inspiration and motivation. The ICU nurses examined believe strongly that nurse-led follow-up is important and valuable for ICU patients and that it can influence patients' recovery. As such, these ICU nurses strive to individualise nurse-led follow-up practices in order to add meaning to the patients' time at the ICU during a critical illness.

This study is based on ICU nurses' experiences of nurse-led follow-up. More research on the follow-up needs of ICU patients and their families is needed to explore their perspectives on nurse-led follow-up. In addition, considering the ICU nurses' reports of being inspired by and gaining knowledge from patients' ICU experiences, further research into the extent to which their job motivation is increased in general by participating in nurse-led follow-up could be a fruitful avenue for future research.

Conflict of interest statement

No conflicts of interest are declared by the authors.

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References

Aitken, L.M., Rattray, J., Hull, A.M., 2017a. The creation of patient diaries as a therapeutic intervention - for whom? Nurs. Crit. Care 22 (2), 67–69. https://doi.org/10.1111/nicc.12286.

Aitken, L.M., Rattray, J., Kenardy, J., Hull, A.M., Ullman, A.J., Le Brocque, R., et al., 2017b. Perspectives of patients and family members regarding psychological support using intensive care diaries: An exploratory mixed methods study. J. Crit. Care 38, 263–268. https://doi.org/10.1016/j.jcrc.2016.12.003.

Angel, S., Vatne, S., 2017. Vulnerability in patients and nurses and the mutual vulnerability in the patient-nurse relationship. J. Clin. Nurs. 26 (9–10), 1428–1437. https://doi.org/10.1111/jocn.13583.

Backman, C.G., Orwelius, L., Sjoberg, F., Fredrikson, M., Walther, S.M., 2010. Long-term effect of the ICU-diary concept on quality of life after critical illness. Acta Anaesthesiol. Scand. 54 (6), 736–743. https://doi.org/10.1111/j.1399-6576.2010.02230.x.

Beeby, J.P., 2000. Intensive care nurses' experiences of caring. Part 2: Research findings. Intensive Crit. Care Nurs. 16 (3), 151–163. https://doi.org/10.1054/iccn.2000.1490.

Benner, P., Tanner, C.A., Chesla, C.A., 2009. Expertise in Nursing Practice : Caring, Clinical Judgment & Ethics. Springer, New York.

Benner, P., Wrubel, J., 1989. The Primacy of Caring : Stress and Coping in Health and Illness. Addison-Wesley, Menlo Park, California.

Bradbury-Jones, C., Sambrook, S., Irvine, F., 2009. The phenomenological focus group: an oxymoron? J. Adv. Nurs. 65 (3), 663–671. https://doi.org/10.1111/j.1365-2648.2008.04922.x.

Carel, H., 2009. A reply to 'Towards an understanding of nursing as a response to human vulnerability' by Derek Sellman: vulnerability and illness. Nurs. Philos. 10 (3), 214–219. https://doi.org/10.1111/j.1466-769X.2009.00401.x.

Cuthbertson, B.H., Rattray, J., Campbell, M.K., Gager, M., Roughton, S., Smith, A., et al., 2009. The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: a pragmatic randomised controlled trial. BMJ 339,. https://doi.org/10.1136/bmj.b3723 b3723.

Doody, O., Slevin, E., Taggart, L., 2013. Focus group interviews in nursing research: part 1. Br. J. Nurs. 22 (1), 16–19. https://doi.org/10.12968/bjon.2013.22.1.16.

Ednell, A.K., Siljegren, S., Engstrom, A., 2017. The ICU patient diary-A nursing intervention that is complicated in its simplicity: A qualitative study. Intens. Crit. Care Nurs. 40, 70–76. https://doi.org/10.1016/j.iccn.2016.12.002.

Egerod, I., Christensen, D., 2009. Analysis of patient diaries in Danish ICUs: a narrative approach. Intens. Crit. Care Nurs. 25 (5), 268–277. https://doi.org/10.1016/j.iccn.2009.06.005.

Egerod, I., Risom, S.S., Thomsen, T., Storli, S.L., Eskerud, R.S., Holme, A.N., Samuelson, K.A., 2013. ICU-recovery in Scandinavia: a comparative study of intensive care follow-up in Denmark, Norway and Sweden. Intens. Crit. Care Nurs. 29 (2), 103–111. https://doi.org/10.1016/j.iccn.2012.10.005.

Egerod, I., Storli, S.L., Akerman, E., 2011. Intensive care patient diaries in Scandinavia: a comparative study of emergence and evolution. Nurs. Inquiry 18 (3), 235–246. https://doi.org/10.1111/j.1440-1800.2011.00540.x.

Elliott, D., Davidson, J.E., Harvey, M.A., Bemis-Dougherty, A., Hopkins, R.O., Iwashyna, T.J., et al., 2014. Exploring the scope of post-intensive care syndrome therapy and care: engagement of non-critical care providers and survivors in a second stakeholders meeting. Crit. Care Med. 42 (12), 2518–2526. https://doi.org/10.1097/CCM.0000000000000525.

Engstrom, A., Andersson, S., Soderberg, S., 2008. Re-visiting the ICU Experiences of follow-up visits to an ICU after discharge: a qualitative study. Intens. Crit. Care Nurs. 24 (4), 233–241. https://doi.org/10.1016/j.iccn.2008.03.002.

Engstrom, A., Rogmalm, K., Marklund, L., Walivaara, B.M., 2015. Follow-up visit in an ICU: receiving a sense of coherence. Nurs. Crit. Care. https://doi.org/10.1111/nicc.12168.

Engstrom, A., Soderberg, S., 2010. Critical care nurses' experiences of follow-up visits to an ICU. J. Clin. Nurs. 19 (19–20), 2925–2932. https://doi.org/10.1111/j.1365-2702.2009.03162.x.

Ewens, B., Chapman, R., Tulloch, A., Hendricks, J.M., 2014. ICU survivors' utilisation of diaries post discharge: a qualitative descriptive study. Austr. Crit. Care 27 (1), 28–35. https://doi.org/10.1016/j.aucc.2013.07.001.

Garrouste-Orgeas, M., Coquet, I., Perier, A., Timsit, J.F., Pochard, F., Lancrin, F., et al., 2012. Impact of an intensive care unit diary on psychological distress in patients and relatives. Crit. Care Med. 40 (7), 2033–2040. https://doi.org/10.1097/CCM.0b013e31824e1b43.

Giorgi, A., 1997. The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. J. Phenomenol. Psychol. 28 (2).

Giorgi, A., 2005. The phenomenological movement and research in the human sciences. Nurs. Sci. Q. 18 (1), 75–82. https://doi.org/10.1177/0894318404272112.

Giorgi, A., 2009. The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach. Duquesne University Press, Pittsburgh, PA.

Giorgi, A., 2012. The descriptive phenomenological psychological method. J Phenomenol. Psychol. 43, 3–12.

Gjengedal, E., Ekra, E.M., Hol, H., Kjelsvik, M., Lykkeslet, E., Michaelsen, R., et al., 2013. Vulnerability in health care–reflections on encounters in every day practice. Nurs. Philos. 14 (2), 127–138. https://doi.org/10.1111/j.1466-769X.2012.00558.x.

Gjengedal, E., Storli, S.L., Holme, A.N., Eskerud, R.S., 2010. An act of caring - patient diaries in Norwegian intensive care units. Nurs. Crit. Care 15 (4), 176–184. https://doi.org/10.1111/j.1478-5153.2010.00402.x.

Glimelius Petersson, C., Ringdal, M., Apelqvist, G., Bergbom, I., 2015. Diaries and memories following an ICU stay: a 2-month follow-up study. Nurs. Crit. Care. https://doi.org/10.1111/nicc.12162.

Griffiths, J.A., Barber, V.S., Cuthbertson, B.H., Young, J.D., 2006. A national survey of intensive care follow-up clinics. Anaesthesia 61 (10), 950–955. https://doi.org/10.1111/j.1365-2044.2006.04792.x.

Jensen, J.F., Egerod, I., Bestle, M.H., Christensen, D.F., Elklit, A., Hansen, R.L., et al., 2016. A recovery program to improve quality of life, sense of coherence and psychological health in ICU survivors: a multicenter randomized controlled trial, the RAPIT study. Intens. Care Med. 42 (11), 1733–1743. https://doi.org/10.1007/s00134-016-4522-1.

Jonasdottir, R.J., Jonsdottir, H., Gudmundsdottir, B., Sigurdsson, G.H., 2018. Psychological recovery after intensive care: Outcomes of a long-term quasi-experimental study of structured nurse-led follow-up. Intens. Crit. Care Nurs. 44, 59–66. https://doi.org/10.1016/j.iccn.2017.06.001.

Jonasdottir, R.J., Klinke, M.E., Jonsdottir, H., 2016. Integrative review of nurse-led follow-up after discharge from the ICU. J. Clin. Nurs. 25 (1–2), 20–37. https://doi.org/10.1111/jocn.12939.

Jones, C., Backman, C., Capuzzo, M., Egerod, I., Flaatten, H., Granja, C., et al., 2010. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised, controlled trial. Crit. Care 14 (5), R168. https://doi.org/10.1186/cc9260.

Karnatovskaia, L.V., Johnson, M.M., Benzo, R.P., Gajic, O., 2015. The spectrum of psychocognitive morbidity in the critically ill: a review of the literature and call for improvement. J. Crit. Care 30 (1), 130–137. https://doi.org/10.1016/j.jcrc.2014.09.024.

Knowles, R.E., Tarrier, N., 2009. Evaluation of the effect of prospective patient diaries on emotional well-being in intensive care unit survivors: a randomized controlled trial. Crit. Care Med. 37 (1), 184–191. https://doi.org/10.1097/CCM.0b013e31819287f7.

McPeake, J., Shaw, M., Iwashyna, T.J., Daniel, M., Devine, H., Jarvie, L., et al., 2017. Intensive care syndrome: promoting independence and return to employment

(InS:PIRE). Early evaluation of a complex intervention. PLoS One 12, (11). https://doi.org/10.1371/journal.pone.0188028 e0188028.
Moi, A.L., Storli, S.L., Gjengedal, E., Holme, A.N., Lind, R., Eskerud, R., et al., 2018. The provision of nurse-led follow-up at Norwegian intensive care units. J. Clin. Nurs. https://doi.org/10.1111/jocn.14379.
Needham, D.M., Davidson, J., Cohen, H., Hopkins, R.O., Weinert, C., Wunsch, H., et al., 2012. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit. Care Med. 40 (2), 502–509. https://doi.org/10.1097/CCM.0b013e318232da75.
NICE. 2009. Rehabilitation after critical illness in adults. NICE clinical guideline 83. Retrieved from http://pathways.nice.org.uk/pathways/rehabilitation-after-critical-illness#path=view%3A/pathways/rehabilitation-after-critical-illness/rehabilitation-after-critical-illness-overview.xml&content=view-index
O'Connell, E., 2008. Therapeutic relationships in critical care nursing: a reflection on practice. Nurs. Criti. Care 13 (3), 138–143. https://doi.org/10.1111/j.1478-5153.2008.00273.x.
Perier, A., Revah-Levy, A., Bruel, C., Cousin, N., Angeli, S., Brochon, S., et al., 2013. Phenomenologic analysis of healthcare worker perceptions of intensive care unit diaries. Crit. Care 17 (1), R13. https://doi.org/10.1186/cc11938.
Schofield-Robinson, O.J., Lewis, S.R., Smith, A.F., McPeake, J., Alderson, P., 2018. Follow-up services for improving long-term outcomes in intensive care unit (ICU) survivors. Cochrane Database System. Rev. 11, CD012701. https://doi.org/10.1002/14651858.CD012701.pub2.
Scholtz, S., Nel, E.W., Poggenpoel, M., Myburgh, C.P.H., 2016. The culture of nurses in a critical care unit. Global Qual. Nurs. Res. 3, 1–11. https://doi.org/10.1177/2333393615625996.
Segaric, C.A., Hall, W.A., 2015. Progressively engaging: constructing nurse, patient, and family relationships in acute care settings. J. Fam. Nurs. 21 (1), 35–56. https://doi.org/10.1177/1074840714564787.
Storli, S. L., Eskerud, R. S., Gjengedal, E., Holme, A. N., & Synnevåg, H., 2011. Nasjonale anbefalinger for bruk av dagbok til pasienter ved norske intensivavdelinger. Retrieved from https://www.nsf.no/Content/795419/cache=20131609132806/Nasjonale%20anbefalinger%20for%20bruk%20av%20dagbok.pdf.
Svenningsen, H., Langhorn, L., Agard, A.S., Dreyer, P., 2015. Post-ICU symptoms, consequences, and follow-up: an integrative review. Nurs. Crit. Care 22 (4), 212–220. https://doi.org/10.1111/nicc.12165.
Ullman, A.J., Aitken, L.M., Rattray, J., Kenardy, J., Le Brocque, R., MacGillivray, S., Hull, A.M., 2015. Intensive care diaries to promote recovery for patients and families after critical illness: A cochrane systematic review. Int. J. Nurs. Stud. 52 (7), 1243–1253. https://doi.org/10.1016/j.ijnurstu.2015.03.020.
Van Der Schaaf, M., Bakhshi-Raiez, F., Van Der Steen, M., Dongelmans, D.A., De Keizer, N.F., 2015. Recommendations for intensive care follow-up clinics; report from a survey and conference of Dutch intensive cares. Minerva Anestesiol. 81 (2), 135–144.
Vouzavali, F.J., Papathanassoglou, E.D., Karanikola, M.N., Koutroubas, A., Patiraki, E. I., Papadatou, D., 2011. 'The patient is my space': hermeneutic investigation of the nurse-patient relationship in critical care. Nurs. Crit. Care 16 (3), 140–151. https://doi.org/10.1111/j.1478-5153.2011.00447.x.